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ABSTRACT

A model to serve rural (Kentucky) mentally retarded adults age 50 and over incorporates generic community resources such as residential, nutritional, medical, recreational, and transportation services with age appropriate activities and programs. The system is intended to provide an alternative to the life-long work setting of the workshop or work activity center and to the residential setting of nursing homes and personal care homes. Currently the program serves 20 people in weekly individualized service coordination. The program director's role has evolved to advocacy, social planning, and managing. The second phase of the project will focus on developing residential options. A new project in Lexington is in the planning stages and four other regional boards are exploring the idea and feasibility of starting age appropriate services for the older person with mental retardation. (CL)

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The Aging and Elderly Population with Mental Retardation: A Model Project in Rural Kentucky

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Aging and Elderly Demonstration Project

Since 1945, the population with mental retardation has experienced an increase in life expectancy which is approaching the life span of the population without handicaps. Before 1945, the life expectancy of this population was 35 years. Now due to changes in environmental conditions, medical advancement, and developments in the modality of services, this population has increased while at the same time becoming almost invisible. During the last five years around the country, there has been a growing interest in the service needs of the aging and elderly population with mental retardation. Traditionally, services to the MR population have been available to children and young adults with few options or programs developed for the aging population { age 50 and over}. Today the major services are long term custodial care and sheltered workshops or work actitivities. This brings up the questions; *Should a person with mental retardation be required to work all of his life until he is physically unable or dead? And should the only options for residence be institutional or family?* A study in the state of New York revealed that of the aging population across their state, 7.8% of the aging population was mentally retarded. As applied to the state of Kentucky, there is a possibility that 32,735 aging adults with mental retardation are living here. In the past four fiscal years, the Regional MH / MR Boards {the planning bodies responsible for community services} have reported an increase of services to those clients above the age of 65 { 14 in FY 81-82, and 140 in FY 84-85 }.

The project I have chosen to discuss was a conceptual model program developed in Kentucky by James A. Stone , D.D. Coordinator for the Kentucky Division of Mental Retardation . Its purpose was to provide appropriate services to those individuals living in rural communities who are in transition from the work age to that of retirement years . A rural area was chosen due to the geographical makeup of Kentucky and the fact that according to the census bureau, 80% of the state is considered to be rural.

A shortage of funds and the expectation that "other agencies" were providing services has contributed to the void of service delivery to the aging person with mental retardation ; however, the experience shows that other *normal* elderly populations have not readily accepted the aging

population with mental retardation anymore than they accepted them when they were young. Service agencies have not filled the void.

The model.

The concept incorporates the individuals' abilities and needs for service planning and delivery of age appropriate activities and programs with as much intergration in the existing community resources as possible. The goal is to replicate this program in other regions of the state. The program is flexible in the types of services available to the elderly population. Some of the services which are necessary are: companion services, transportation, housekeeping assistance, recreational / social outings, and generic community resources .

Examples of generic community resources are:

Service / Need	Provider
Residential	(1) HUD housing for the handicapped (2) Shared home or apartment (3) Supervised apartments,etc.
Nutritional	Community center, meals on wheels, food stamps, home maker services
Medical	Home health, clinics for senior citizens,local health departments, medical assistance cards
Recreation	Senior Citizens centers, churches, community education programs, community colleges, social organizations, Regional MH/MR Boards , etc.
Transportation	Available community transit system, handicapped service, private car, taxi, senior citizens centers, churches,Regional MH/MR Boards

Case management Regional MH/MR Boards

The model has the necessary flexibility to develop program people who are capable of working with the needs of the MR population , understand the aging needs , and interact on a favorable basis with those agencies which are now providing services to the normal aging population. There must be the opportunity to provide assistance to the aging person with mental retardation in settings other than in nursing homes or personal care homes . Alternatives to the life-long work setting of the workshop or work activity center must be developed. Another objective of the model is to provide linkages to other resources and funding such as social security, medicare, medicaid, social services and personal resources .Another important element is educating the client to the various eligibility formats to access those community programs that are in existence. Transportation must be available for those clients being served.

The model should demonstrate the possibility of serving aging people handicapped by developmental disabilities in rural areas with program choices other than work oriented or no services. It should explore the possibility of residential options, socialization opportunities, and other social services available. In addition, it is important to determine the number of possible clients who may be in need of these transitional services. This can be accomplished by using the available records from social security, CHR data, and other community referral agencies. The first six months of the project will concentrate on staff development, client need identification and the implementation of the model with a target of 10 to 12 people receiving various services as their needs indicated. The Division of Mental Retardation will provide technical assistance and expertise throughout the project period and also assist in coordination of the involvement of other appropriate service agencies.

Client Services.

The project started client services on December 1, 1985 , with three client referrals. By April 1, 1986, 35 people had been referred from three counties in the five county region. Currently, 20 individuals with an average age of 63.4 years are involved in weekly individualized service coordination . Two major needs in the rural area are transportation and medical attention; 60% of the first group of clients have two or more medical / or health related problems in addition to mental retardation, 15% have one additional impairment , while 25% have no additional problems. The oldest participant is 81 and the youngest is 51. Transportation of aging individuals may require the use of larger sized automobiles or older station wagons rather than buses , vans, or compact cars. The mobility limitations , as a result of the aging processes and further compounded by the other health or physical impairments , can quickly complicate the accessibility of specific services.

As the project progressed from the conceptual period to the implementation period, the role of the program director evolved to one of being an advocate , a social planner, and a manager. Eighteen community agencies have participated in providing services to the elderly population with mental retardation in one of the more rural service areas in the state. They are: the Kentucky Department of Social Services , the Department of Social Insurance, Denham Clinic, Meadowview Regional Hospital, Licking Valley Community Action Program, Senior Citizens Program, County Health Departments, Homemakers Club in Mason County, Maysville Arts Council, Pioneer Trace Nursing Home, Bracken Center , Maysville Extended Care, Y.M.C.A., Hayswood Home Health, Retired Senior Volunteer Program, Trinity Methodist Church , Maysville Public Library, and the University of Kentucky Chandler Medical Center.

One of the major objectives of the model is to use the resources in the community without creating a 5 day per week "drop-off" program. While the Regional MH-MR Board provides four rooms which include a kitchen, an office, and two meeting rooms, no one is allowed to be at the center more than 3 days per week. The same policy is extended for the senior citizen centers. Due to the use of a station wagon for transportation, only four people and the coordinator or part time assistant are out in the community at once. The community restaurants , stores, and public

services i.e., the library , health department, courthouse, and community education classes, are utilized for social outings and participation in the community. The experience has indiciated the rural nature of the area lends to an acceptance and cooperation of the citizens and the services agencies of our target group .

Previous experience in deinstitutionalization has proven the success of attempting to provide programs and services as the individual needs of each person are evaluated ; this project has continued to do the same, services and program options are offered to each person for their choice. The term "open slot" , or placing a client into an available opening without regard to their actual need , has been eliminated.

Concept vs. Operation.

Originally, the model was constructed to serve 10-12 people in one county . In addition, there was an understanding that new services could be created whenever necessary by using funds in the annual budget. For example, the first survey indicated the probability of using the established senior citizens center was very small. It was anticipated the duplication of hot meals and social activities would be necessary at the project office site. However, by communicating the desire of not to requiring services for each and every hour the senior citizens center was open, acceptance of the project participants has been excellent. It was also realized that our group would be limited in their ability to spend money for their recreation and leisure benefit; therefore, a part of the budget was targeted as small petty cash fund to buy lunches, pay admissions and assist in small emergencies. This component has been valuable and necessary to allow individual participation and assist successful integration into the community.

One brief success story : one of the ladies in the project had been a hospital volunteer for years until her physical appearance and personal hygiene deteriorated and she was "*retired* " by the management of the hospital. At the age of 71 , she was able to return to work as a senior volunteer. The key to Goldie's returning to the job she really enjoyed was the expenditure of $8.00 per week for a beauty shop appointment to have her hair shampooed and "fixed". Some personal counseling with the project coordinator also helped. This is one of many details that have been

addressed to provide new opportunities for this aging population in an effort to assist in using their community and to enjoy the benefits.

The second phase of the project will focus on developing residential options using the individual's resources and / or supplemental resources to move inappropriately placed elderly individuals with mental retardation from nursing homes and personal care homes, or unacceptable community housing. There is a target group of more than 400 people in this environment , plus the "invisible" community residents living with family or relatives who could require placement at anytime. One of the residential options will attempt to match an age appropriate participant with mental retardation with an age appropriate roommate to share housing on a room and board basis. This then will free the nursing home bed , and provide a less restrictive environment while assisting the community resident in the cost of food and housing. The second option will be supervised housing for two handicapped participants as roommates using their personal resources as much as possible to cover the expenses. These options will be available along with the ongoing service coordination in order to provide realistic options and choices to the aging population (as opposed to the choice of day programming, sheltered work, or being excluded from many of the community generic services).

The realization that the life cycle of the aging / elderly individual with mental retardation will be changing due to the actual aging process, the changes in family settings, and the availability or lack of services throughout their lifetime should influence any developing programs to develop the flexibility to change or make exceptions as needed by the individual participant. The mental retardation service providers will need to understand the additional problems and disabilities created by the natural decline of the body by the aging process and understand the possible individual changes in each participant as they enter the retirement years.

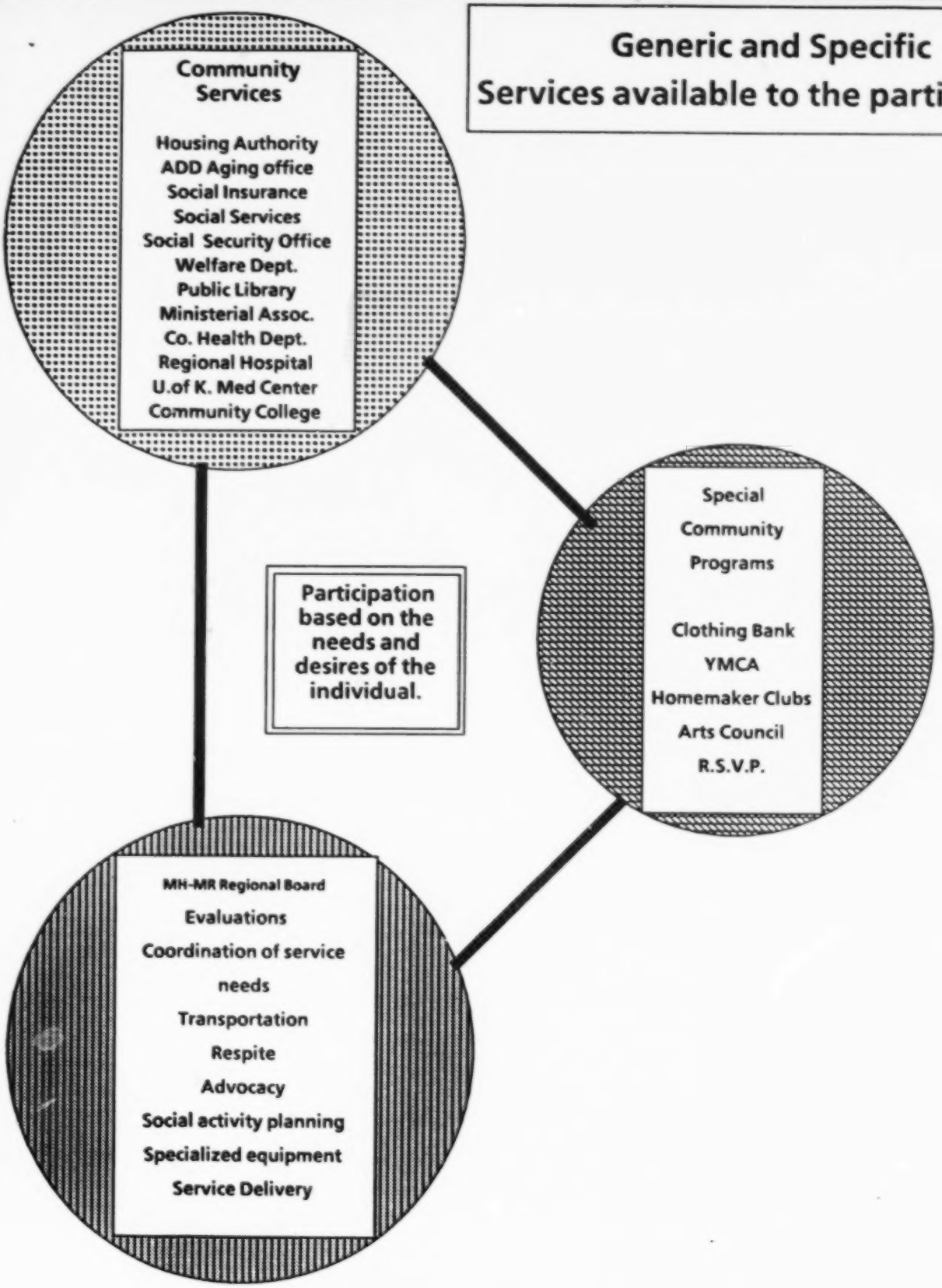
Conclusion.

In conclusion , the first nine months has demonstrated a need for aging related service options and choices for the invisible population wth mental retardation over the age of 50 . Most of these people have not been able to participate in formal educational programs, were adults when the

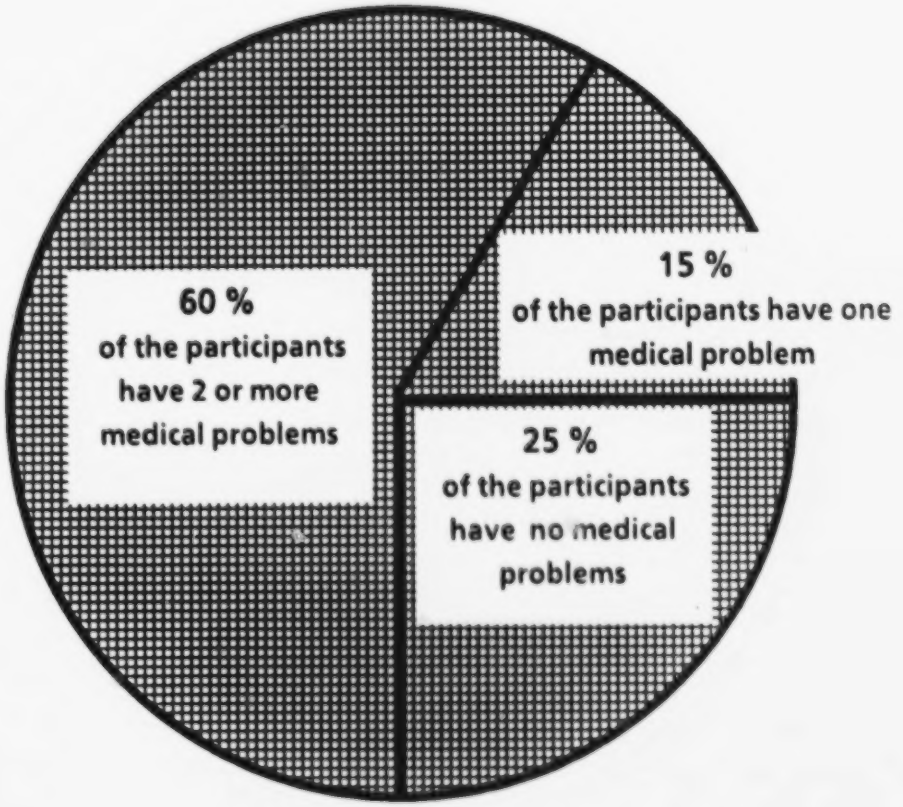
system of regional mental health-mental retardation boards were constructed in the mid 1960's, and have had to wait for specific mental retardation services to "catch up" to them. This group as a whole function at a high level of community awareness while at the same time are very suspicious of anyone who is wanting to assist them in their community. The origin al grant for the project was $48,300 and this has been renewed for a second year. A new project in Lexington is in the planning stages and four other regional boards are exploring the feasibility of starting age appropriate services to the older person with mental retardation.

Attachments

Generic and Specific Services available to the participants



Percent of Participants with medical problems in addition to mental retardation


60 %
of the participants have 2 or more medical problems
15 %
of the participants have one medical problem
25 %
of the participants have no medical problems

hearing impairments,
chronic lung condition,
glaucoma,
care of a heart pace maker,
high blood pressure,
kidney problems,
mobility,
heart disease,
Parkinson's disease,
bursitis,
obesity,
and
emphysema